

# Lynch Syndrome Fact File

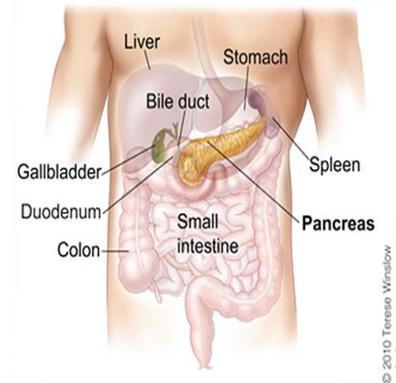
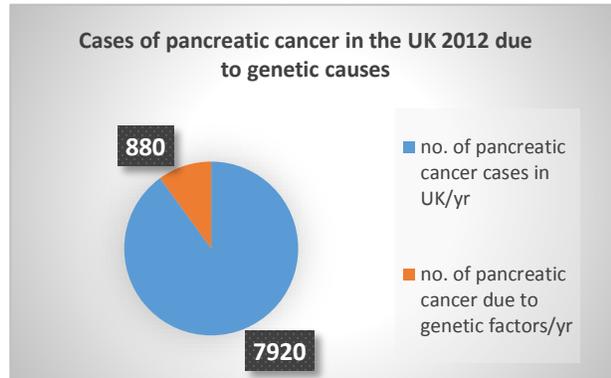
## LYNCH SYNDROME AND PANCREATIC CANCER

by Pauline Skarrott Feb 2016

Cancer of the pancreas is part of the Lynch group of cancers but it is one of the least common in the syndrome.

### HOW COMMON IS PANCREATIC CANCER IN THE UK?

Pancreatic cancer is the 10<sup>th</sup> most common cancer in the UK. Around 8800 people get it in the UK each year, roughly even numbers of men and women.<sup>3</sup>



The average risk of getting pancreatic cancer in the UK by the age of 70 years in the general population is **0.5%**. It is thought that 10% of pancreatic cancers are due to genetic factors but other causes include: smoking, being overweight, having diabetes and being a heavy alcohol drinker.<sup>3</sup> **Smoking** has the greatest effect.

### WHAT IS THE RISK OF GETTING PANCREATIC CANCER IN LYNCH SYNDROME?

The average risk of getting pancreatic cancer for carriers of LYNCH SYNDROME is **4%**, a factor of 9 x normal risk. That means that by the age of 70 yrs, **nearly four people out of a hundred** Lynch syndrome carriers will get pancreatic cancer.<sup>1</sup>

### WHICH LS GENE MUTATIONS ARE MOST AT RISK?

Pancreatic cancer seems to be slightly more common in MLH1 and MSH2 families but more research is needed to determine this.<sup>1</sup>

Some LS families seem to have cluster of 2 or 3 cases of pancreatic cancer. It is not known why this is but trials of screening methods are being done. (see overleaf)

### WHAT AGE DO PEOPLE GET PANCREATIC CANCER IN LS?

The average age that people with Lynch syndrome tend to get pancreatic cancer is around 50 -55 years although it has been recorded as low as 20 years and as old as 80 years.<sup>1</sup> However, the risk is very low at a young age and does not start to rise until **40 years**.

(The average age of pancreatic cancer in the general population is 65years+)

### WHAT ARE THE SYMPTOMS OF PANCREATIC CANCER?

Pancreatic cancer is difficult to diagnose early and therefore act promptly if you have LS and get any of the symptoms below. You should not have to wait more than a couple of days. Take a specimen of urine with you.

**Pain in the upper abdomen**, just under the breast bone, typically "gnawing" in quality and spreading round or through to the back. It tends to be constant but may come and go, worse on laying down, better when leaning forward. It may persist for days or weeks.

**Jaundice**, affecting skin, whites of eyes and urine which all go bright yellow. Urine does not lighten with drinking more fluids.

**Weight loss** that is unexplained can be very significant especially with one or two of the other symptoms.

(For more detail about pancreatic cancer symptoms go to:

[www.cancerresearchuk.org/about-cancer/type/pancreatic-cancer/about/pancreatic-cancer-symptoms](http://www.cancerresearchuk.org/about-cancer/type/pancreatic-cancer/about/pancreatic-cancer-symptoms)

## INVESTIGATIONS FOR PANCREATIC CANCER

These are done by a surgical team at hospital with investigations that include blood tests, scans and xrays.

## TREATMENT FOR PANCREATIC CANCER

Treatment usually involves surgery together with chemotherapy and/or radiotherapy.

The 5 year survival is 6%.<sup>3</sup> The outlook for people with pancreatic cancer has been poor because in most cases it is diagnosed late in the illness and if it has spread to adjacent organs, it may be inoperable. That is why symptom awareness and Europac's new screening trial are especially important for all Lynch syndrome carriers.

## WHAT SCREENING IS AVAILABLE IN THE UK FOR PANCREATIC CANCER IN LYNCH SYNDROME?

Screening has not yet been proven to improve the outcome of pancreatic cancer in the UK and is not yet generally available in the NHS.

## SCREENING UNDER EUROPAC

Europac is an organization that is doing European trials on screening for pancreatic cancer in Lynch syndrome families in the UK and is accepting the following people onto their trial:-

**"Anyone over the age of 40 who is a carrier of a Lynch syndrome related mutation in MLH1, MSH2, MSH6, PMS2 or EPCAM who also has a relative with the same mutation and pancreatic cancer is likely to be considered by Europac for pancreatic cancer screening and should either contact their GP or EUROPAC directly ([europac@liv.ac.uk](mailto:europac@liv.ac.uk)). EUROPAC will also consider individuals with a Lynch syndrome related mutation if they have a first degree relative who had pancreatic cancer even if it is unknown whether the relative carried the mutation."**

Screening is performed at specific NHS hospitals in the UK - Liverpool , Newcastle, UCH, London, Southampton, Glasgow, Nottingham, Leeds, and Bristol.

You might be offered one or more of the following:-

\*blood tests such as genetic tests, fasting glucose and CA19-9

\*EUS (endoluminal ultrasound)

\*OGD oesophago-gastro-duodenoscopy (endoscope through the stomach and takes samples from the area where pancreas drains into the duodenum)

\*CT scan (computerized tomography scan)

[www.europac-org.eu](http://www.europac-org.eu) tel no 0151 706 4168 email [europac@liverpool.ac.uk](mailto:europac@liverpool.ac.uk)

## OTHER WAYS OF PREVENTING CANCER OF THE PANCREAS IN LS

10% of pancreatic cancers are genetic but the following factors also play a part.

\*Take aspirin longterm (dose at least 100mg daily)

\*Don't smoke

\*Keep your weight normal and prevent diabetes by eating healthy, low sugar diet

References.

1.Kastrinos F, "Risk of pancreatic cancer in families with Lynch syndrome" Jama Oct 28 2009  
<http://jama.jamanetwork.com/article.aspx?articleid=184783>

2.Vasen European guidelines 2013 Gut

3.Cancer research UK [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

